

Research Advisory Committee on Gulf War Veterans' Illnesses

**Committee Meeting Minutes
June 11 and 12, 2019**

**U.S. Department of Veterans Affairs
Washington, DC**

Research Advisory Committee on Gulf War Veterans' Illnesses
Committee Meeting Minutes

I hereby certify the following minutes as being an accurate record of what transpired at the June 11 and 12, 2019, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.



Lawrence Steinman, M.D.
Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Attendance Record

Members of the Committee:

Dr. Lawrence Steinman, Chair
Ms. Kimberly Adams
Dr. James Baraniuk
Mr. Brent Casey
Ms. Marilyn Harris
Dr. Stephen Hunt
Dr. Katherine McGlynn
Mr. Jeffrey Nast (not present)
Ms. Frances Perez-Wilhite (not present)
Dr. Carey Pope (not present)
Dr. Scott Rauch (telephone)
Dr. Mitchell Wallin
Dr. Scott Young (not present)

Designated Federal Officer:

Dr. Karen Block

Committee Staff:

Mr. Stanley Corpus
Mr. John Rukkila
Ms. Marsha Turner

Invited Speakers:

Mr. Robert Wilke, Secretary VA
Mr. Jeffrey Moragne, VA ACOMO, DC
Ms. Carol Borden, VA General Counsel, DC
Dr. James N. Woody, San Francisco, CA
Dr. Erin Dursa, VA Office of PDHS, DC
Dr. Kenneth S. Ramos, Texas A&M University
Dr. Peter D. Rumm, VA Office of PDHS, DC

RAC-GWVI Subcommittee Members:

Dr. Lawrence Steinman, Chair
Dr. Karen Block, DFO
Ms. Kimberly Adams
Mr. Brent Casey
Ms. Marilyn Harris
Dr. Drew Helmer
Dr. Stephen Hunt
Mr. William “Bill” A. Watts

Veteran Roundtable Discussion Participants:

Chaplain Barrington Malcom
Mr. George Coates
Mrs. Ruth Coates
Mr. Brian Davis
Ms. Haley Davis
Mr. Randy Harrod
Mr. Bill Watts

Veterans:

Ms. Andrea Freedom
Mr. Ken Hiltz
Ms. Tracy Johnston (spouse)
Ms. Denise Nichols

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses (RAC-GWVI)
Department of Veterans Affairs**

**LOCATION: Sonny Montgomery Room (Room 230)
810 Vermont Ave NW, Washington, DC 20420**

Call-in: (800) 767-1750; access code 56978#

Watch Online: <http://va-eerc-ees.adobeconnect.com/racgwvi-june2019/>

**Agenda
Tuesday, June 11, 2019**

9:00 – 9:15	Welcome and Opening Remarks	Dr. Karen Block, Designated Federal Officer
	Welcome, Overview and Introductions	Dr. Lawrence Steinman, Chair Res Adv Cmte on GW Veterans' Illnesses
9:15 – 9:30	Federal Advisory Committee Training	Jeffrey Moragne, Director VA Advisory Committee Management Office
9:30 – 10:15	Ethics Training	Carol Borden, Ethics Staff Attorney VA Office of General Counsel
10:15 – 10:45	VA Updates on RAC-GWVI Recommendations and GW Program	Dr. Karen Block VA Office of Research and Development
10:45 – 11:00	Break	
11:00 – 11:30	Overview of First Gulf War Environment	James N. Woody, MD, PhD CAPT MC USN (Ret) Former: Commanding Officer, Navy Medical Research and Development Command
11:30 – 12:00	How Participation in Gulf War Veteran Research Can Impact Change: The Big Picture	Erin Dursa, PhD, MPH Post-Deployment Health Epidemiology Program
12:00 – 1:00	Lunch	
1:00 – 1:10	Veteran Engagement Session (VES) Roundtable Overview and Instructions	Lawrence Steinman, MD
1:10 – 1:30	VES Overview Houston / Cleveland	Marylyn Harris / Kimberly Adams
1:30 – 1:50	VES Key Topic Reports	VES Subcommittee Members
1:50 – 3:00	Veteran Attendee Experiences	Veterans and Supporters
3:00 – 3:30	VES Roundtable Discussion/Questions	Invited Guests and RAC VES Subcommittee
3:30 – 3:45	Break	
3:45 – 4:30	Committee Discussion	Dr. Lawrence Steinman, Chair Res Adv Cmte on GW Veterans' Illnesses
4:30 – 5:00	Public Comment	
5:00	Adjourn	

Veteran Engagement Session (VES) Roundtable Discussion

Agenda

- 1:00 – 1:10 Roundtable Overview and Instructions Lawrence Steinman, MD**
- 1:10 – 1:30 Roundtable Overview: VES Meetings**
- Houston VAMC: Marylyn Harris
 - Cleveland VAHCS: Kimberly Adams
- 1:30 – 1:50 VES Key Topic Reports**
- What health issues are of greatest concern to Gulf War Veterans?..... Steve Hunt, MD
 - How can research improve the treatments available to GW Veterans? Karen Block, PhD
 - What health issue could VA address to improve GW Veterans’ quality of life?. Marylyn Harris
 - What would you like the VA Secretary to know about health of GW Veterans? **Lawrence Steinman, MD**
- 1:50 – 3:00 Veteran Attendee Experiences**
- Chaplain Barrington Malcolm, Houston
 - Randy Harrod, Cleveland
 - George Coates and wife Ruth
 - Brian Davis and daughter Haley
- 3:00 – 3:30 Discussion / Questions**
- RACGWVI Committee address VES
 - Audience address VES
 - Phone / Facebook / other address VES

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**Agenda
Wednesday, June 12, 2019**

9:00 – 9:30	Introductory Remarks and Welcome to VA Leadership	Dr. Lawrence Steinman, Chair Res Adv Cmte on GW Veterans' Illnesses
9:30 – 10:00	Discussion with VA Leadership	Senior VA Leader Dept. of Veterans Affairs
10:00 – 10:30	Generational Health Effects of Serving in the Gulf War	Kenneth Ramos, MD, PhD Professor of Medicine, Texas A&M Committee Chair, National Academy of Medicine, Vol 11, Gulf War and Health
10:30 – 11:00	Post-Deployment Health Update and Initiatives	Dr. Peter Rumm, Director VA Pre-9/11 Era Environmental Health Program
11:00 - 11:15	Break	
11:15 – 12:00	Committee Discussion	Dr. Lawrence Steinman, Chair Res Adv Cmte on GW Veterans' Illnesses
12:00 – 12:30	Public Comment	
12:30	Adjourn	

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
(RAC-GWVI)
U.S. Department of Veterans Affairs**

Tuesday, June 11th, 2019

Committee Meeting Minutes

Welcome and Opening Remarks

— **Dr. Karen Block, VA Office of Research & Development and Designated Federal Officer, RAC-GWVI**

Dr. Block announced the meeting as a public meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses and noted a quorum for this committee was present in person and on the phone. She provided orientation to the conference room, meeting sign in, teleconference phone contact, and public comment. She welcomed Research Advisory Committee (RAC) members and alternative Dedicated Federal Officer and thanked RAC administrative staff for pulling the meeting together.

Welcome, Overview and Introductions

— **Dr. Lawrence Steinman, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses**

Dr. Steinman called the meeting to order and welcomed committee members, speakers, and guests. He reviewed the Veteran Engagement Sessions held by the RAC earlier in the year and the Roundtable follow-up to be held in the current meeting. He noted that the RAC will consider the information provided in making decisions and providing advice on what research ought to be done about Gulf War illness. He introduced the presenter for the Federal Advisory Committee Act and ethics training. As the meeting sessions progressed, Dr. Steinman introduced committee members, speakers, and guests.

Session 1: Federal Advisory Committee Training

— **Jeffrey Moragne, Director, VA Advisory Committee Management Office**

Mr. Moragne briefed RAC members on providing successful recommendations as advisory committee members. He reviewed the Federal Advisory Committee Act charter, committee structure, membership, terms of service, applicable regulations, and standards of conduct. He discussed what constitutes a FAC meeting and best practices for conducting meetings. He requested that committee members read the VA Committee Member Handbook.

Session 2: Ethics Training

— **Carol Borden, Ethics Staff Attorney, VA Office of General Counsel**

Ms. Borden reviewed categories and application of ethics rules. She discussed conflicts of interest, standards of conduct, laws and regulations, and restriction on political activities pertaining to government employees.

Session 3: VA Updates on RAC-GWVI Recommendations and GW Program

— **Dr. Karen Block, VA Office of Research and Development**

Dr. Block reviewed the Veterans Health Administration (VHA) Office of Research and Development (ORD) mission, vision, funding, and programs. She described active Gulf War research projects, outcomes, and translation from bench to bedside. She reviewed cooperative studies projects, multi-center clinical trials, epidemiology studies, research leadership training, and VA-DoD synergy and coordination.

Dr. Block discussed progress of the Project IN-DEPTH Gulf War illness sister protocol being conducted by the VA in partnership with the National Institutes of Health for investigative deep phenotyping of Gulf War Veteran health.

Session 4: Overview of First Gulf War Environment

— **James N. Woody, MD, PhD, CAPT MC USN (Ret), Former: Commanding Officer, Navy Medical Research and Development Command**

Dr. Woody reviewed the high frequency of unexplained health problems in Gulf War illness across multiple biologic systems and the overall poor health among Gulf War Veterans. Although the epidemiology is well studied, he noted exhaustive studies have not identified a unifying etiology for Gulf War illness. He reviewed progress on potential therapies for Gulf War Veterans' illnesses and the progress of trials for PTSD drug and psychosocial therapies. He answered questions about types of PTSD, novel therapeutic targets, multiple vaccine problems, and generational molecular changes.

Session 5: How Participation in Gulf War Veteran Research Can Impact Change: The Big Picture

— **Erin Dursa, PhD, MPH, Post-Deployment Health Epidemiology Program**

Dr. Dursa reviewed that despite motivation for participation, people don't participate in research studies because of distrust, time commitment, participant burden, and the belief that participation will not have any impact. She reviewed the history of longitudinal research on the variety of symptoms and illnesses reported in Gulf War Veterans soon after the 1990–1991 Gulf War: In 1992, Public Law 102-585 directed the VA to create the Gulf War Registry and to contract with the National Academies to review the health consequences of service during the Persian Gulf War. The 1992 Gulf War Health Registry and 1994 DoD Comprehensive Clinical Evaluation Program were limited for lack of comparison group and inability to establish causation. The 1995–1997 National Health Survey of Gulf War Veterans and their families was the first population-based study to characterize and demonstrate significant burden of disease among deployed Gulf War Veterans. Additional sub-studies from this cohort revealed PTSD and fatiguing syndrome in Gulf War Era Veterans and increased risk of chronic multisymptom illness in spouses and birth defects among children born to Gulf War Veterans. In 2012–2014, follow-up study of a national cohort of Gulf War and Gulf Era Veterans reported a significantly higher prevalence of chronic illnesses. Additional public law policy created the Persian Gulf War Veterans Act and the Veterans Program Enhancement Act that directed the Secretary of the VA to enter into contractual agreement with the National Academy to review and evaluate scientific literature on the relationship between exposures associated with Gulf War service and disease. Dr. Dursa explained that the reviews have been used to make determinations about deployment related exposure and disease relationships and to categorize levels of association between deployment in the Gulf War and conditions reviewed. She noted the impact of research on Gulf War Veterans is reflected in research and clinical practice focus on developing a case definition for Gulf War illness, the Project IN-DEPTH investigative deep phenotyping of Gulf War Veteran health, and the development of the War Related Illness and Injury Study Centers.

Session 6: Veteran Engagement Session (VES) Roundtable Overview and Instructions

— **Lawrence Steinman, MD, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses**

Dr. Steinman reviewed the two Veteran Engagement Sessions conducted by a RAC Subcommittee earlier this year in Houston, TX, and Cleveland, OH, with the idea to listen and to hear what our Gulf War Veterans had to say and what their major issues were. He stated that he thought the engagement was compelling and the messages were loud and clear. Four individuals from the sessions were invited to participate in roundtable discussion of the major issues that came up.

- **VES Overview Houston / Cleveland. — Marylyn Harris / Kimberly Adams**

Marylyn Harris, subcommittee member from Houston, described the large numbers of Gulf War Veterans living in the Houston area and noted they expressed feelings of being invisible, detached from the VA system, and angry towards the VA. She reported that Gulf War Veterans in Houston experienced a lack of support from the VA clinicians who are not educated about the Gulf War and Gulf War-related illnesses. She said Gulf War Veterans in Houston were skeptical about participating in research and unaware of ongoing Gulf War research.

Kimberly Adams, subcommittee member from Cleveland, cited a similarly large number of Gulf War Veterans who expressed many of the same issues Veterans revealed in Houston, especially that Gulf War Veterans' distrust the VA system. She related the need to recognize exposures, understand the effects showing up now in the Veterans and their families, and provide targeted care. Research issues, she noted, were more about intergenerational effects of Gulf war exposures. The biggest takeaway she said was that "no one knows who we are." She said the Gulf War Veterans and their families deserve to be recognized for the job they did and for the health care issues they have.

- **VES Key Topic Reports. — VES Subcommittee Members**

- **What health issues are of greatest concern to Gulf War Veterans?**

Dr. Hunt reiterated the importance of asking and listening to find out about what Veterans' concerns are. He said what the Veteran will say is, "I want you to hear this. This is what I experienced. Listen to this, this is what I experienced. This is how it affected my life. Listen to that and my family's life. I want you to hear this. Listen to that. This is how I'm doing now." Dr. Hunt emphasized this dialog is needed to learn about the health care issues of greatest concern to our Gulf War Veterans.

- **How can research improve the treatments available to Gulf War Veterans?**

Dr. Block reviewed the many significant medical breakthroughs provided by VA research and how participation in research has promoted understanding of Gulf War illness with the goal of finding cures or treatments to improve the quality of life. She noted Veterans suggested guidance from another Veteran or peer-to-peer support was facilitative for research participation.

- **What health issues could the VA address to improve Gulf War Veterans' quality of life?**

Bill Watts stated the first step to restore Gulf War Veterans trust was to listen, which is what the subcommittee did—hearing concerns, repeated straight from the Veterans in their own communities, that they feel their quality of life begins with quality of care. He emphasized trust, communication, encouragement, and understanding are the way to get this era of Veterans to once again trust the VA.

Marylyn Harris discussed many quality-of-life resources to be compiled and listed on the RAC website. She talked about many free services available to Veterans, positive impact of Veteran Centers, value of health care referrals to the VA War Related Illness and Injury Study Centers, and helpful Veterans Planning Guide support for dignified funerals.

- **What would you like the VA Secretary to know about the health of the Gulf War Veterans?**

Dr. Steinman pointed out that as a Federal Advisory Committee the RAC-GWVI does not directly make recommendations on care. He stated that in treading a very delicate path we certainly want to continue looking at effects of environmental exposures during the Gulf War. He said we can also ask for proposals not on care issues but on effects of trials on various issues facing Veterans. Suggestions can be presented, he said, not about care but as a research study. Dr. Steinman said it is important to push hard on the areas of great strength and ongoing research of the VA. He also emphasized making it easier to participate in and gather specimens for funded research as well as submit regular progress reports and include communication with research participants about outcomes of studies they are involved in.

- **Veteran Attendee Experiences. — Veterans and Supporters**

One Gulf War Veteran described how playing chess helped him regain memory and focus of concentration after his return from Desert Shield/Desert Storm. He noted in teaching Veterans how to cope he is challenged regarding his own struggles: “how can I dance with mine so as I care for Veterans, I can say, ‘Look, this will work, that will work...’ because I’m using it myself?” He emphasized how “Gulf War Veterans often talk about the fact that people just don’t understand them. That’s the main complaint, that they don’t understand. And they want people who can understand them so they can talk to those people.” In summary he stated, “that could be one thing that needs to be addressed: how can we have more Veterans caring for Veterans?”

A call-in Gulf War Veteran noted the War Related Illness and Injury Study Center (WRIISC) in Palo Alto involved their chaplains so that Veterans seen there not only saw the pain doctor but also saw the chaplain. Marylyn Harris agreed that more chaplain interaction is needed in more VA hospitals.

- **VES Roundtable Discussion — Invited Guests and RAC VES Subcommittee**

During the round table discussion, an invited Gulf War Veteran stated he often heard, “Desert Storm is the new forgotten war.” He said, if you say “Gulf War,” most people don’t even think about Desert Shield or Desert Storm. He emphasized that Gulf War Veterans are getting penalized for the success they had in the first Gulf War that was the largest, swiftest, most successful campaign in military history. He noted because the ground war only lasted 100 hours, people say, “There is nothing wrong with you. You can’t have anything wrong. You were hardly there.” But, he said, we’re finding out that’s not the case. Other comments from this discussion include:

- We would like admission by the Department of Defense about being exposed to high levels of chemicals, needs a definitive answer for Gulf War syndrome from the VA.
- More research needs to be done in peer-to-peer counseling, especially for avoidance of suicide in Veterans.
- Every VA center should have a Gulf War Resource Center, with the name “Gulf War Resource Center” on the wall so it doesn’t get confused with anything else, and providers need to be educated in Gulf War syndrome.
- The Veterans Crisis Hotline needs to be a dedicated line, not a line shared with the National Suicide Hotline.
- VA should evaluate pictures/murals on VA clinic walls because some of them can trigger negative reactions in soldiers going there for therapy and it would be an inexpensive way to address concerns.

An invited Gulf War Veteran described how, as an engineer in the U.S. Army, he was activated to go overseas to Saudi Arabia and experienced stress, loss of sleep, and the death of fellow soldiers after Scud missile attacks. Noting that his faith and prayer helped him survive, he said, “We cannot depend just on man, we have to depend on God.”

Spouses of Gulf War Veterans spoke about what effect deployment had on marriage and family and how the war literally changed the entire trajectory of their lives including:

- How she began by dealing with serious illness in her husband when he came home from the war and how he was really crying out for help and the VA minimized his illness. They went to a county hospital where her husband was found to have health problems that required emergency surgery.
- After some time, they gave the VA another try and said it was life changing because now the VA really helped.

- The Veterans wife noted she would like to find a program for wives and for women where you can go and express yourself and hear other people speak about what's going on with them.
- She stated that personally now, after all these years, she needs help with another group of women who experienced their husbands being gone so that we can support each other. Support is very important, she said.
- She concluded that a guy is not going to understand everything that a woman is going through—you still need other women to speak to.

An invited Gulf War Veteran from the U.S. Army described many injuries he received after 17 deployments in the military and time spent in the desert, the dirt, the jungle.

He explained how an exploding mine caused serious wounds, including blindness, resulting in ongoing health problems as well as follow-up issues with Gulf War illness symptoms that he is having a tough time understanding.

He described being deployed with the 82nd Airborne and experiencing not only wartime direct effects on himself but now also generational effects on his daughter. Some of the concerns included:

- His biggest issue, he said, is not knowing what his wartime exposures are doing to his daughter, to her DNA, and not only her DNA, but also her children and their DNA, the effects possibly getting stronger and stronger.
- He emphasized, “As a parent, I think all that we have to think about is family.”
- Gulf War Veterans received multiple rounds of vaccinations required for a forward unit, and he was exposed to the black and slimy soot and smoke of burn pits and oil fires.
- He concluded, “My story is my children's story. That's my legacy, my children. That's what I live for. That's who I fought for.”
- His 19-year-old daughter spoke about what effect Veteran wartime experiences have on the child of a Gulf War Veteran.
- She noted that she had never been to the Gulf War, but she is the child of a Gulf War Veteran and has the same symptoms as a Veteran, which really shows there is a connection and symptoms are going from generation to generation.
- They believe as a result of her father’s injections and exposures, she also now has many serious health issues that she has endured with great courage and can describe in detail.
- She reported it will be extremely difficult for her to have a child and her risk of miscarriages has increased by about 30 or 40 percent.
- She said she is dealing with the constant stress of not knowing what's going to happen to her.
- She told how doctors refused to test for certain things because they said she is too young to have medical conditions.
- She concluded, “This is an issue that the Veterans have passed on, and I think that the VA needs to accept responsibility for that, and they need to figure out something for the children because I'm not the only one.”

During the Roundtable Discussion, other Veterans spoke on the phone line and described similar intergenerational problems occurring with their children. They also noted three websites related to children of Veterans: one is dedicated just to Desert Storm, a second is OIF and OEF and Desert Storm, and a third is just combat Veterans.

• **VES Roundtable Questions. — Invited Guests and RAC VES Subcommittee**

Dr. Steinman noted the importance of getting on the record any questions submitted by meeting attendees online or by phone. Dr. Block read questions submitted and committee members provided comment.

- A Veteran wrote: “Many years ago, I signed up for the Gulf War Registry and went through some tests. I have been curious about what it is doing. I have never been asked back for any follow-up. I don't know if my VA medical records ever got included.”
 - Dr. Rumm offered to contact the Veteran and responded that the Veteran’s primary care provider could access records from the Gulf War Exam. He also noted to contact their VA facility Environmental Health Coordinator about access to Registry information.
- A Veteran wrote to ask whether the RAC-GWVI could “be a resource for Veterans to help show plausibility of symptoms to Gulf War service?” The statement continued:

“In the current system, the onus is on the veteran to provide evidence of connection, which is crazy in my view. I spent 9 months in Jubail, S.A. Within 13 or 14 months of my return, I experienced paralysis of my left hand, speech defects, and numbness and tingling on the left side of my body. I spent 30 days in the Pittsburgh VA, underwent a whole host of diagnostic tests, including the brain biopsy. The VA gave me a diagnosis of isolated intracranial vasculitis. I had brain lesions in the white matter.

“Because of this diagnosis with no known etiology my ongoing symptoms, anxiety, memory loss, concentration issues, challenges with executive decisions, and communication issues do not fall under presumptive illness definition. I am health conscious. I exercise regularly and follow a vegetarian diet, and intelligent individual who rarely speaks health care and works hard to compensate those on these ongoing issues.

“They have, however, definitely taken their toll on my career and my quality of life. My VA claim has been denied repeatedly because I cannot provide evidence of connection to my Gulf War service. This is where Veterans need help. I hope your committee will consider cases such as mine in the work that you plan to do. Thank you for the work you do now.”

 - Kimberly Adams, JD, who works with claims, responded: First, try to make it a secondary condition if they've already awarded you benefits. Second, fill out the Disability Benefits Questionnaire form that is on the VA site or take it to your VA physicians to fill out to get the VA language needed for a claim. Dr. Rumm offered to help and added this is the kind of person that should get a Gulf War Registry Exam and eventually get referred by their VA primary care doctor to the WRIISC.
- A Veteran wrote to ask about a study that may influence decisions about presumptives:

“What are they going to do with the BU study published this year? I want to know if there are going to be more presumptives added.”

 - Dr. Dursa responded that the question appears to be about a paper looking at Gulf War Veterans and the prevalence of health care issues in the general U.S. population, which will be reviewed the National Academy to make a determination if the science is strong enough and robust enough to establish an association. Dr. Rumm confirmed the review is a very robust three-level process with results eventually sent to the Secretary of the VA.
- A Veteran wrote to ask: “Is our service and lives less valuable than the money that they don't want to spend? Where--why are there no TV ads to tell the Vets how to get help?”
 - Dr. Steinman replied: I think it's a good question. All I can say is we've noted it now, and obviously it's a tough one to answer, but we'll make sure it's disseminated hopefully to people who can give such an answer.

Committee Discussion

— Lawrence Steinman, MD, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Dr. Steinman opened the discussion for RAC members to review the various issues that had arisen.

Marylyn Harris reviewed the richness of the Veteran Engagement Sessions and that though sometimes very painful the memories were very necessary. She said she was empowered to be a little braver and go with a fellow Veteran to the Houston Veterans Cemetery, which she had not previously been able to go to because it was too painful. She said she is now able to tell her story of tragedy and resilience that is like the story of many women veterans.

Dr. Hunt expressed gratitude at being able to work with Veterans to figure out what might be helpful to them and their families. He said implementation of research is incredibly important and to look at different ways of approaching taking care of Gulf War Veterans with treatment models to see how they compare and what are the best ones.

Marsha Turner asked how can we get more people enrolled in research studies? She noted perhaps we need to approach them at the Veteran Center where they feel safer and more comfortable telling a story.

Dr. Baraniuk discussed incorporating common data elements into the medical record for individual Veterans with a pull-down menu that tells the physician there is a Gulf War illness and cues up the key common illnesses to ask about. He suggested to address the concerns of the Veterans and help the clinicians by adding a family history section that asks, "How is your spouse? Problems with your children?" As an aspect of quality control, he would get a list of publications and citations supported by the VA and compare that to CDMRP to check whether the Congressionally Directed Medical Research Program has a much greater impact than the VA-funded work. He also noted that with the NIH study it would be very reasonable to understand the continuity of the process for developing that protocol and how it's progressing with recruitment and any outcomes as they come along.

Dr. McGlynn agreed with the promise of results from the IN-DEPTH study but also emphasized the importance of just listening to people tell their story.

Dr. Wallin said he was impressed with all the testimonies that were heartwarming and good to hear. He also noted the power of big data surveillance and a big network to use it effectively. He said he thinks we can make inroads into linking data together with genomics and even some of the registries.

Kimberly Adams said to keep it simple, keep it creative, and keep inspiring. She noted it is our job to keep educating about what is going on, and incorporate the research, and incorporate all things that this committee does.

Brent Casey said he is very honored and humbled and a little bit overwhelmed in his first go-around and opportunity to serve the RAC as a representative of Gulf War Veterans.

Dr. Block said to think about gaps in the field. In reference to comparing notes with DoD to find out publications and information being published, she noted it is hard to track because people don't always cite their work. However, she revealed, she is working with the Gulf War Research Resource Center for VA to pull out all the people who have been published, been funded, from VA since day one. She said this review will find the outcome of those studies—who completed, who didn't complete, what publications resulted—so we can start tracking that. With this process, she concluded, we can identify gaps and try to form new collaborations that might be able to bring some research forward.

Dr. Steinman concluded the discussion with thanks to all the participants, outstanding speakers, and Veterans with their moving and compelling stories. He noted the engagement sessions proceeded effectively at the big centers with big catchment areas and he would also like to see what would happen at smaller centers in more rural districts. He noted a lot was heard and in making recommendations to the Secretary we should try to give the highest priority to the most compelling needs. He turned the meeting over to public comment.

Public Comment

Participants in person and on the phone line made public comments covering a wide range of topics.

Denise Nichols, Gulf War Veteran and advocate, asked for a plan forward, short- and long-term goals, and whether the RAC would have other meetings for scientific-type work besides the Veteran Engagement Sessions. She recommended going to Minneapolis because you've got a four- or five-state area there as well as VA researchers; she also suggested Alabama, Denver, and New Mexico. She asked for more WRIISCs or at least champions for Gulf War illness. She noted the Gulf War had an air war that went on longer and it should be emphasized. She proposed the need at VA Central Office for a Desert Storm complaint line. She asked why can't the VA intramural research have Veteran participation in the same way that CDMRP has Veterans participating in the review process? She advocated for getting early and later photographs of Veterans into their medical record to provide comparisons for weight gain.

Denise suggested having knowledgeable Gulf War Veterans do once-a-month orientation sessions for Veterans at a VA with providers getting continuing medical education credits for participating. She noted two recently published medical papers about doing a research project on educating providers so that better care and research can come out of it.

Dr. Block confirmed investigator-initiated research projects of this kind are looking at Gulf War Veterans' care from a Patient Aligned Care standpoint versus a specialized team. Dr. Steinman replied we could consider something like that for the issue of long-range planning, but we need to be careful. He referred to the RAC 2018 long-range plan recommendation that in late 2019 is still under deliberation by the VA.

Ken Hiltz, a Cleveland-area Marine Veteran, provided a written comment: "Please share with the committee about the recommendations I received from Ohio Health and Central Behavioral Health that I should cease going to the Columbus VA for Gulf War issues, health issues. Aside from my optometrist and my current primary care physician, Persian Gulf War issues, health issues, are viewed as a myth at the Columbus VA clinic. Multiple Columbus Clinic physicians have told me to seek care outside the VA, and I did exactly that. Please relate to the board, the VA executive staff, and Gulf War veterans in the VISN 10 that work at Ohio Health Clinicians and Syntero Behavioral Health of Central Ohio, which is in the Columbus area, will accept new patients with issues associated with deployment to the Persian Gulf War."

Veteran Andrea Freedom asked what research is being done for those who served after the initial invasion to current day that have been affected by the same symptoms as the initial invasion folks?

Dr. Hunt replied that the clinical practice guidelines that we came up for chronic multisymptom illness are not specific to Gulf War Veterans. We do see Veterans from other deployments with a similar syndrome that we don't know whether it's exactly the same thing or not. That's why we actually advocated when the Institute of Medicine recommended changing the terminology from "Gulf War illness" to "chronic multisymptom illness," that we should at least put a qualifier on there, "chronic multisymptom illness in Gulf War deployed Veterans," because we're not sure whether or not there is something unique about that group and the way it manifests itself. But the clinical practice guidelines regardless will also help Veterans from other deployments that have similar constellations of symptoms like fatigue and cognitive disturbances, memory concentration problems, and chronic pain and so on. Many of the same techniques and approaches that might offer some help to Gulf War Veterans could also help these other Veterans as well.

Andrea Freedom added that her question stemmed from personal frustration and trying to get help and treatment, and it had been basically to no avail for a good year and a half or so since her health started to decline. She said she was just looking for answers and what can help and what doesn't, and what is believable. She said she would walk in somewhere and tell them what's going on, and they would reply "There's no way, you're only 38." Well, she confirmed, there is a way because it's happening.

Dr. Hunt offered support from him or Dr. Rumm to direct some resources that may be able to help. Dr. Dursa noted recent study findings that fifty percent of the OEF/OIF/OND Veterans were meeting the criteria for symptoms of chronic multisymptom illness and Gulf War illness.

Tracy Johnston, whose husband Brian is a Gulf War Veteran, said she was very happy that for the first time in 28 years someone was listening, actually engaging with the Veterans, and keeping the discussions simple. She noted Brian was not in combat but when he worked on military vehicles from the battlefield he was exposed to depleted uranium and developed health problems with symptoms of immunodeficiency. Tracy noted the need for the RAC to look at immunodeficiency in these Veterans.

Kimberly Adams, Gulf War Veteran and RAC subcommittee member, who was deployed in air support noted how effective the Veteran Centers have been for her. She pointed out that to qualify to use a Veteran Center you don't have to be a Veteran that was in combat, just a Veteran of a combat era. She noted the eligibility requirement for Veteran Center services: All Veterans are encouraged to seek Veteran Center services—any Veteran and active duty servicemembers, to include members of the National Guard and reserve components are eligible.

Bill Watts, Gulf War Veteran and RAC subcommittee member, pointed out that Veterans were noting being concerned with premature aging, loss of bone density, and loss of teeth. He said the RAC needs to look at this and Veterans need to get in touch with Dr. Nancy Klimas in Miami for immunological problems.

Adjourn

Dr. Steinman, Chair for the RAC-GWVI, adjourned Day 1 of the Committee meeting and announced resumption for Day 2 of the Committee meeting on Wednesday, June 12th, at 9:00 a.m.

**Meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses
(RAC-GWVI)
U.S. Department of Veterans Affairs**

Wednesday, June 12th, 2019

Committee Meeting Minutes

Introductory Remarks and Welcome to VA Leadership

— **Dr. Lawrence Steinman, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses**

Dr. Steinman called the meeting to order. Dr. Block reminded everybody that the meeting is on the record, will be transcribed, and will be made public. Dr. Steinman announced the VA Secretary would come for discussion and there would be no comments other than from the committee. He thanked the Veterans and family members who spoke and said he thought the presentations by our Veterans were moving, compelling, and taught very important lessons about what some of the requirements are for our committee and the messages that we need to give as we advise on research policy.

Committee Discussion

— **Lawrence Steinman, MD, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses**

Dr. Steinman asked committee members to give their reactions to the previous day's meeting.

Brent Casey said he thought it was a very productive day and he was honored to be here.

Dr. Wallin said it was great to hear more from Gulf War Veterans themselves and hearing some new voices and new issues was helpful. He added that talks about ongoing surveillance are important in a cohort 25 years from the actual conflict. He said there is a need to survey periodically over time as people age and compare results to appropriate control groups. He noted the surveillance part gives clues and some can be drilled down with more intensive analyses or other specific targeted assessments.

Dr. Baraniuk stated knowing the clinical needs of veterans was very important and helps to reassess current problems to pull together into new research issues and questions that return as diagnostics and treatments for Veterans. He added the RAC should continue to address the National Institutes of Health (NIH) study epidemiology and review the complete protocol of the study.

Dr. Block and Dr. Steinman reviewed details of the NIH-VA partnership still being under scientific review and not timely for the RAC to give input. They discussed the 2018 RAC recommendation to evaluate the progress of the deep phenotyping study and ensure support from ORD to follow up leads, continue the project forward, and develop investigator access to a biorepository. Dr. Wallin noted the RAC had input on specific aspects of the deep phenotype study including what would be done with samples and how they would link the biorepositories.

Marsha Turner emphasized building on the future direction of research and the importance of participating in research, making it understandable, and spreading the word to get people into studies.

Dr. Hunt said we are making progress to support Gulf War Veterans and all combat-deployed Veterans. He said we need to be really expansive in our definition of research because it's research that guides clinical care always. He emphasized the need to leverage the electronic health record to serve both research and serve clinical care. He noted the importance of listening to our Veterans to be guided and informed in our research and in our clinical care through Veterans' stories about their needs.

Marylyn Harris said to keep in mind to speak about Veterans, Gulf War Veterans, in terms of their localities because it's not the same everywhere. She stated we have a unique opportunity to create a

network of Gulf War Veteran ambassadors who can be armed with accurate information, resources, and knowledge of ongoing research.

Dr. Block stated in summary that all research has to be driven by the Veterans, what they are saying, not what we think are great ideas.

Session 7: Discussion with VA Leadership

— **Lawrence Steinman, MD, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses**
— **Robert Wilkie, Secretary VA**

Dr Steinman welcomed Secretary Wilke and asked committee members to introduce themselves.

Secretary Wilke started by relating the great transformation occurring in the VA with significant shifts in population of Veterans from Northeast and Midwest into the South. He noted not only demographic but also cultural shift as Gulf War Veterans replace Vietnam to become the largest contingent and change the way the VA does business. Secretary Wilke stated the MISSION Act is incredibly important to enable Gulf War Veterans to use the private sector if VA cannot provide a service. He noted the Act fulfills the mandate of Congress by putting Veterans as the center of Veterans' health care as opposed to the needs of the institution. He said it puts Veterans on a level playing field with fellow citizens by creating an option for urgent care.

Secretary Wilke addressed Veteran suicide as his number-one clinical priority that he will address in front of Congress. He argued that America needs a whole health approach to this issue with additional focus on mental health, homelessness, and addiction. He pointed to Gulf War Veterans as leading a cultural shift to change the way service members talk about what they have experienced, to ask for assistance, and to tell people you have an issue that you need to discuss. He said the new culture also includes new ways of treating pain with therapies such as acupuncture, tai chi, and aqua therapy. As part of the reform, Secretary Wilke said he supports the need to build an interoperable electronic health record to encompass Veterans' entire service record and provide a valuable research tool.

To answer a question about engaging Gulf War Veterans to get them back into using VA services, Secretary Wilke pointed out a recent *Annals of Internal Medicine* report saying that VA health care is as good or better than any in the private sector. Also, the very recent full implementation of the Act should improve care coverage and payment problems and as services get better and wait times improve, more and more people are coming to us, he stated.

Dr. Steinman reviewed the success of the new Veteran Engagement Sessions and the Veterans' disappointing experiences with VA doctors' recurring lack of knowledge about the Gulf War and related health issues. He talked about the RAC mission to determine how to sculpt research and give advice that will enable this to be improved. He gave as examples the importance of determining the molecular basis of suicide and mental illness as well as developing templates in the electronic health record to record military experiences of Veterans.

Secretary Wilke complimented Dr. Steinman on the good points he made and then participated in a group photograph with committee members and follow-up personal discussions with Veteran guests and committee members.

Session 8: Generational Health Effects of Serving in the Gulf War

— **Kenneth Ramos, MD, PhD, Professor of Medicine, Texas A&M, Committee Chair, National Academy, of Medicine, Vol 11, Gulf War and Health**

Dr. Ramos reviewed the new National Academy committee assessment of current research available on possible generational health effects that may have resulted from exposures experienced by Veterans' deployment in the 1991 Gulf War and Post-9/11 war: The committee considered reproductive, developmental, and generational effects associated with Gulf War toxicants and developed approaches to

study and monitor potential problems related to impact of Veterans' deployments on their children and grandchildren. The Committee followed the evaluation process established by previous Gulf War and Health and other National Academy committees and listed categories of association between deployment in the Gulf War and conditions reviewed. Dr. Ramos emphasized the importance to focus on the lessons learned and he invited the RAC to learn from previous studies and use proper scoping and leveraging of existing resources in the Veteran community to get the information needed.

Session 9: Post-Deployment Health Update and Initiatives

— Dr. Peter Rumm, Director, VA Pre-9/11 Era Environmental Health Program

Dr. Rumm reviewed discussions on the National Academy of Medicine report on Gulf War and Health, Volume 11, Generational Health Effects of Serving in the Gulf War, to determine how the report recommendations can be used. He discussed current registry surveillance programs, their strategies and limitations, and the proposed future Individual Longitudinal Exposure Record. He noted prevalence data on Gulf War exposures and study group overview of health conditions in Gulf War Veterans. Dr. Rumm reviewed the case definition chart abstraction validation project review of VHA electronic medical records to identify and confirm Gulf War illness status according to three base case definitions.

Committee Discussion

— Lawrence Steinman, MD, Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

Dr. Steinman asked for open discussion from RAC members on any remaining issues that had arisen.

Dr. Baraniuk asked what is the plan and agenda for the next meeting? Dr. Steinman replied October 3rd and 4th in San Francisco and next year certainly one in Washington, DC, and others away from our bicoastal tradition. Dr. Steinman noted our best feature of this meeting was hearing from the Veterans directly and that performance can be repeated. Dr. Baraniuk also asked what currently funded VA research would be appropriate to present at future RAC meetings? Later, Dr. Baraniuk noted the chronic fatigue organization, International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, meeting has had a large contingent of Gulf War illness presentations and investigators. He suggested it would be a good opportunity to consider having a Gulf War illness state-of-the-art one-day addition to that meeting.

Dr. Wallin said it would be good to get some presentation updates on the Cerner health record to make sure there is integration of deployment and era as well as integration with our current registries, including war, cancer, and neurologic registries. He pointed out the need to discuss how the omics, the Million Veteran Program, would integrate with our research platform and the servers required for imaging data.

Dr. Hunt suggested Drs. Block and Steinman express an interest through the Secretary's office to have the Office of Electronic Health Record Modernization provide an update. He said this would help shape our recommendations around some of the potentials for the electronic health record in the service of research. Marsha Turner added there is an information technology working group handling these big issues and how to work with research.

Further discussion proceeded among committee members about DNA data extraction and status of the Million Veteran Program and Millennium cohort. The PTSF Brain Bank in Boston, the Tucson VA Alzheimer's Brain Bank, and the Gulf War Brain Bank were discussed and suggested as possibilities to get some presentations for funded VA researchers.

Marylyn Harris and Kimberly Adams discussed raising awareness about research studies that can help improve people's quality of life, the richness of information received by the RAC, and how to get the fruits of the information out to the Veteran community. They also discussed how racial and ethnic communities and subcategories of Veterans also don't know about research, and we need to make sure our communication efforts match our dedication to the research at hand. Dr. Wallin responded to suggest using the meeting as a springboard to do some local education or awareness of research studies and

recruitment. Marylyn Harris stated that people are desperate for information and that is part of our charge, our job, to give it to them, through our website and links to clinicaltrials.gov. Dr. Baraniuk asked if *Military Times* had reported on these meetings or if we could record the meeting to be shown as an infomercial on military television. Later he also noted other organizations, including the NIH, have career and predevelopment travel awards that allow increasing numbers of junior members to attend presentations that get research issues out there. Ms. Adams added that we can't silo ourselves and not get this information out; it has to get out to the Veterans that can't be here.

Dr. Hunt discussed the need to be more intentional about community-based participatory research where we really look at the Veteran community as partners and really have specific recommendations on how to educate researchers and engage communities in research.

Marylyn Harris discussed how she successfully interacted and shared information with and learned from other Advisory Committees. Marsha Turner noted the Advisory Committee for Rural Health does team meetings in rural areas and their approach may be of interest for the next Veteran Engagement Session. Dr. Wallin responded that it would also be good to engage with the Department of Defense to get contact and information with people in their military years and keep these folks engaged or make them part of a survey.

Marylyn Harris noted the Secretary's comment that the Gulf War Veteran population would be the largest population in the VA by the end of this year. She noted that although he was speaking overall about the OEF/OIF/OND Veteran population using VA services, it gives us a huge opportunity to spread the information about who we are, our mission, what we do, and to share research with these Veterans and their families.

Dr. Block brought up an outside-the-box idea of advocating career development and maybe a training program for Veterans' children or Veterans themselves who might like to do research by pairing them up with VA investigators. She noted we would not only train people interested in health care, but also get Veterans and their children interested in research to bridge a lot of what we have been talking about. Dr. Steinman commented that it's really bidirectional to get participation of participants and researchers—the participants ask the really tough questions.

Dr. Steinman discussed trying harder to get more live participants from the outside, particularly from the community, to come to the meeting. He recognized the work, appointment, and travel issues that inhibit in-person participation at the meeting and wondered whether a visual teleconference format might be a bridge to ensure the telling of stories remains impactful. He also noted a need to be flexible in scheduling and location, perhaps with weekend meetings, to help get Veterans to participate and meet with us. He summarized that the Veterans participate so we can know the story and see the person and how it actually impacts them.

Public Comment

Participants in person and on the phone line made public comments covering a wide range of topics.

Bill Watts, Gulf War Veteran and RAC subcommittee member, stated that many Veterans note on social media and websites that they would be more able to participate in clinics and research after hours, after 4:00 pm on weekdays, or on weekends.

Chaplain Malcolm from Cleveland stated his disappointment at the lack of attention to the serious challenges he described after his service in the Persian Gulf. He inquired about getting more information about the issue he is struggling with. Dr. Block stated she will send Malcolm some published papers about his health conditions and encouraged him to get follow-up imaging studies. Dr. Rumm added that the WRIISC in California has specialized expertise that may be helpful and could be arranged as a referral follow-up to a Registry Exam.

Denise Nichols, Gulf War Veteran advocate attending the meeting, inquired about the locations of training session held by the WRIISC and whether providers trained could do town hall meetings in their

locations not only for Veterans but also to train other providers, benefits people, and adjudicators. She pointed out that we are not utilizing audiovisual connection capabilities through the Internet that other federal agencies, including the VA, use to connect groups for training, testimony, and presentations. Denise suggested starting a basic registry for Gulf War Veterans' offspring and for spouses that have problems so we can get some data to start from.

Brian Davis, Gulf War Veteran Sergeant Major retired from the U.S. Army, provided follow-up about the Gulf War Babies and Parents United website discussed in the Roundtable discussion yesterday. He also announced that he would love to be a Gulf War champion to speak at VAs. He said he is very satisfied with his VA care and would like to participate in the Depleted Uranium Registry, to which Dr. Block replied that follow-up is being arranged.

Haley Davis, 19-year-old daughter of Brian Davis, reported that the Gulf War Babies and Parents United website has at least 1,000 participants who actively want to find solutions to their problems and many would be willing to participate in research.

Michelle a Veteran on the phone line reported she saw and shared an article from the *Military Times* about children of the Gulf War. She described the health problems of her Gulf War Veteran husband and that her son is ill just like her husband.

A Veteran from Ohio on the phone line described two providers who had experience and wisdom about Persian Gulf War health issues, unfortunately his discussion was largely inaudible as a result of problems with computer feedback. This speaker was able to note that a clinician told him the Persian Gulf War was a limited duration conflict with minimum casualties that was quickly forgotten by the American public, which is why you're not getting what you need and have to go outside the VA.

Adjourn

Dr. Steinman, Chair for the RAC-GWVI, adjourned the Committee meeting and announced the Committee will meet again in October 2019.

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